Hunter's Hope Foundation

2013 Annual Report



Krabbe and Leukodystrophies Expanded and Universal Newborn Screening Dear Friends,

When we were told that our beautiful four-month-old son, Hunter, had Krabbe Leukodystrophy, a disease with no treatment and no cure, our world crumbled. We were given no hope. In fact, we were told he likely wouldn't see his second birthday.

Our hearts were filled with so many shattered hopes and dreams for our son—we thought Hunter would follow in his daddy's footsteps. But God had other plans...



Now, as a family, through the Foundation we created in his honor, we try to follow in *Hunter's* footsteps, to bring hope to others, regardless of what life brings.

Two thousand thirteen was another amazing year for Hunter's Hope and we are in awe of how far we've come since the Foundation began in 1997.

Now, there *is* a treatment for Krabbe, and hope for early detection through newborn screening as more states are screening for Krabbe at birth. We have the promise of improved treatments and ultimately a cure and the future is more hopeful than ever, thanks to the groundbreaking work carried out daily at the Hunter James Kelly Research Institute. And, our Leukodystrophy family continues to grow as we now have the privilege of serving over 700 affected families through our Family Programs.

Yes, there is more work to be done. Join us and together, we will continue to give children like Hunter the hope and support they so desperately need.

Let's press forward together...

With Hope, Jim, Jill, Erin and Camryn Kelly

Mission

Hunter's Hope was established in 1997 by Jim Kelly and his wife Jill, after their infant son, Hunter (2/14/97—8/5/05) was diagnosed with Krabbe Leukodystrophy, an inherited fatal nervous system disease.

While Jim and Jill have been blessed with the opportunity to share Hunter's story and the hope of the Foundation named after their son all over the world - their greatest passion is to bring encouragement and hope to families in the midst of suffering.

Hunter's Hope Foundation was established to address the acute need for information and research with respect to Krabbe Disease and other Leukodystrophies. In addition, we strive to support and encourage those afflicted and their families as they struggle to endure, adjust and cope with the demands of these fatal illnesses.

Accordingly, our mission is:

- To broaden public awareness of Krabbe Disease and other Leukodystrophies thus increasing the probability of early detection and treatment.
- To increase newborn screening standards across the United States to obtain early detection for all diseases where early diagnosis can improve the quality of the child's life.
- To gather and provide current, functional information and service linkages to families of children with Leukodystrophies.
- To fund research efforts that will identify new treatments, therapies and ultimately, a cure for Krabbe Disease and other Leukodystrophies.
- To establish an alliance of hope that will nourish, affirm and confront the urgent need for medical, financial and emotional support of family members.

Core Values

We believe...

...that we must remain true to and passionate about our core ideology
...that we must live and preserve our family-oriented and wholesome image
...in respecting and valuing individual contributions
...in truthfulness and honesty in all matters
...in respecting the right of privacy of all individuals

Education and Awareness

Hunter's Hope is passionate and committed to broadening awareness about Krabbe, Leukodystrophies, and Newborn Screening—we'll continue our efforts until they are commonly understood in the medical community *and* amongst the general population. Our aim is to promote accurate diagnosis and treatments for children affected by Krabbe and other Leukodystrophies, as well as nationwide early detection and treatment through newborn screening.

Furthermore, by increasing public awareness about the work of the Foundation, we strive to obtain additional support as we serve the Krabbe and Leukodystrophy community through family care programs, research into better treatments and cure, and advocacy for newborn screening.

The Kelly Family

As co-founders of Hunter's Hope, Jim and Jill Kelly, together with their daughters, Erin and Camryn, are dedicated to carrying out the overall mission and goals of the Foundation. The Kellys see each book, speaking engagement, interview, *everything*, as an opportunity to broaden public awareness about Hunter's Hope and our mission.

Kelly Family Books

The Kellys have been blessed with the opportunity to share their story of hope in writing. Their books contain information about Hunter's Hope, Krabbe and other Leukodystrophies, and Newborn Screening. In addition, a portion of the proceeds benefit Hunter's Hope.

Jill Kelly's Growing Ministry

In 2013, Jill was invited to participate as the opening speaker at the *Women of Joy* conferences. Through this amazing opportunity, Jill toured seven cities across the country, sharing her story with over 30,000 women, the vast majority of whom where unfamiliar with the Kelly family story and Hunter's Hope. After each event, hundreds waited in long lines to purchase the Kelly family's books and to meet Jill, sharing how her story had impacted their lives.





Jill Kelly Speaking at Women of Joy

Every Sister

Jill had numerous speaking engagements throughout 2013, attended by over 30,000 women in 12 states. Through the Every Sister program a bridge was established, educating the women she encounters about Hunter's Hope and our mission. Every Sister gives these women the opportunity to pray, advocate and give—drawing them into the Hunter's Hope community.



Jim Kelly and fellow Hall of Fame member John Elway showing off MyFanClips

Jim's Money Clip

MyFanClip was launched in 2013. It is a custom designed multipurpose clip that can be used as a money clip, large paper clip, clip for food storage, bookmark or other uses. Jim is using this new venture as a means to increase knowledge of Hunter's Hope, while donating a portion of the proceeds to the Foundation named for his son.

Jim Kelly's Every Score

Every Score is a fun way for football fans to show support for their team and Hunter's Hope at the same time. Through Every Score, Buffalo Bills fans make pledges to Hunter's Hope for every point scored by the Bills. In 2013, the total number of pledges increased by 33% with the total amount donated almost doubling. When the Bills win, we ALL win!

Most importantly, participants are given information about Hunter's Hope, Leukodystrophies and Newborn Screening each week and on the Jim Kelly's Every Score iPhone App.



Email marketing messages sent to Hunter's Hope supporters within states of Buffalo Bills weekly opponents, introducing them to children in their home state, affected by Krabbe and other Leukodystrophies

Social Media

In 2013, the Hunter's Hope Facebook page had a 25% increase of followers. In the coming year, the Foundation plans to continue to enhance our use of various social media platforms to maximize the outreach and information provided through each page.

Expanded and Universal Newborn Screening

For the past 50 years, virtually all of the more than 4 million babies born in the U.S. each year have undergone newborn screening. Newborn screening is a state-based health program to screen newborns for dozens of diseases that are not clinically detectable at birth. Because each state determines what diseases to screen for, there is a great disparity in newborn screening from state to state.

Hunter's Hope advocates for expanded newborn screening, not only for Krabbe and similar disorders, but all possible diseases. For these diseases, early detection is crucial in getting affected children the treatment needed to prevent irreversible mental and physical disabilities, even death.

Newborn Screening – State by State Newborn Screening for Krabbe and Similar Disorders

Last year, families affected by Krabbe and similar disorders continued to advocate for change in their states. In 2013, legislation for newborn screening for Krabbe and similar disorders was introduced in Tennessee, Oregon, California and Jim's home state, Pennsylvania. Families in several other states continue now to work to that end and in 2013 alone, more than 7,000 emails were sent to lawmakers across the country, urging them to support Krabbe newborn screening.



A newborn baby girl in NY State has her heel priced for her newborn screening test

Hannah's Law

In October of 2013, Jim joined several Pennsylvania families to ask their lawmakers to pass *Hannah's Law*, which would add Krabbe and similar diseases to the state's newborn screening panel. While there, Jim met with Pennsylvania Governor Tom Corbett, numerous legislators, and reporters in support of the bill.

Aidan's Law

Thanks to the Seeger family, and many other families and organizations, New York passed and implemented *Aidan's Law*, making New York the first state to screen for Adrenoleukodystrophy, or ALD, another type of Leukodystrophy.

Top: Jim Kelly speaking to lawmakers in Pennsylvania about *Hannah*'s Law

Bottom, Left to Right: Andrea Moran (Director, Hunter's Hope), Elisa and Bob Seeger (Aidan's Parent's), Diane and Butch Rypma (Madison's Grandparents) at the New York State 50 Year Celebration of Newborn Screening



Newborn Screening – Federal Efforts

Newborn Screening Saves Lives Reauthorization Act

Jim and members of the Hunter's Hope staff spent a day in Washington, D.C., asking congressmen and senators to support the Newborn Screening Saves Lives Reauthorization Act. This bill will provide desperately needed funding for state newborn screening programs, parent and medical provider education, and federal programs that help advance newborn screening throughout the country.





Left: Jim Kelly and the Monaco family speaking with lawmakers about the Newborn Screening Saves Lives Reauthorization Act.

Above, Left to Right: Erin Connors (Clinical Care and Research, Hunter's Hope), Jim Kelly, Dietrich Matern, MD, PhD, (Mayo Clinic), and Anna Grantham (Newborn Screening, Hunter's Hope) in Washington, DC

50th Anniversary of Newborn Screening

In the Fall of 2013, Jim accepted an invitation to speak at the 50th Anniversary of Newborn Screening Celebration in Washington, D.C. Participation in this event led to widespread media coverage raising awareness about this important issue, and helped strengthen the Foundation's position in the newborn screening community at large.

The Hunter's Hope staff has also continued their participation in various committees and collaboratives at the state, regional and federal level throughout the newborn screening community, to ensure a voice is given on behalf of those affected by Krabbe and similar disorders.



Jim Kelly and a panel of guests at the 50th Anniversary of Newborn Screening Celebration in Washington, DC

Supplemental Newborn Screening

Throughout 2013, parents from around the world continued to purchase Supplemental Newborn Screening Packets from the Hunter's Hope website, enabling them to make sure their child is screened for Krabbe and 60 other disorders, no matter where they live.

Hunter's Day of Hope and Prayer for Children



Above: Jim and Jill Kelly joined together on stage with children at the Annual Hunter's Day of Hope & Prayer for Children event to join in prayer for children all over the world

Hunter's Hope seeks to inspire an appreciation to God for *all* children. Hunter's Day of Hope and Prayer for Children helps fulfill this primary goal -- to remind parents how blessed they are to have the gift of children and to thank God for them everyday.

Our ultimate goal is to have a *global* Day of Hope & Prayer for Children each year, making this an international day for people throughout the world pray for all children.

In Western New York, we celebrate this special time each year on the Saturday closest to February 14th, as it is both Hunter and Jim's birthday. Families spend time having fun together during a free community event hosted by Hunter's Hope. Most importantly, at this event, families gather together and pray for *all* children. This year was our largest event to date, with over 4,000 enjoying the event, held at the Buffalo Bills Fieldhouse.

For those outside of the Western New York community we encouraged participation through a virtual celebration, through social media and the Hunter's Hope website.

Additionally, New York Governor Andrew Cuomo officially declared February 14, 2013, as Hunter's Day of Hope and Prayer for Children statewide!





Left: The Resolution's presentation on the floor at the New York State Assembly.

Right: Billy the Buffalo (Official Mascot of the Buffalo Bills) poses with a young girl at the 15th Annual Hunter's

Day of Hope & Prayer for Children event

Special Events

In 2013, over \$246,000 was raised through various special events held throughout the year.



Tom and Cynthia Rosicki with Jim and Jill Kelly at the 9th Annual Rosicki Gala

Dine Out for Hope

For one night in December, sixteen restaurants in Western New York gave a portion of their proceeds to Hunter's Hope. Customers enjoyed great food and learning more about our mission.

Rosicki Gala

Hunter's Hope collaborated with Rosicki, Rosicki and Associates, LLP to execute the 9th Annual Rosicki Gala at the Hunter James Kelly Research Institute to bring awareness to the institute among the cliental of the law firm, resulting in over 200 attendees, many of which had never been to or seen the Hunter James Kelly Research Institute.



Jim Kelly on-air for the Hunter's Hope 550 Auction with 550 talent, "Schopp and Bulldog"

550 Auction

This year, Hunter's Hope partnered with Entercom Buffalo/WGR 550 Sports Radio to raise over \$54,000! Throughout the day, listeners gained a deeper understanding of Krabbe and other Leukodystrophies as well as the importance of newborn screening through interviews with affected families, Jim, and many of his celebrity friends. Various companies and individuals donated items for the auction so that the proceeds from the auction would benefit Hunter's Hope.



The Kelly family shows off their Hunter Kelly jerseys at Coca-Cola field.

Hunter's Hope Day with the Bisons at Coca-Cola Field

Hunter's Hope partnered with the Buffalo Bisons, Class Triple A baseball team this year for another family fun evening at the ballpark. The Foundation was able to share its message with more than 8,500 fans through use of the stadium's video board, raffles and more.

Every Step Walk

Every Step is our national walk to raise awareness and funds to support our mission. The Hunter's Hope staff works with volunteer groups, families, corporations, and organizations, in various locations throughout the country to coordinate and host an Every Step Walk in their local



community. The walk is an effort to engage individuals, families, and organizations across the country to support families affected by Krabbe and Leukodystrophies, fund research and advocate for expanded and universal newborn screening.

In 2013, over 650 walkers participated in nine walks held in seven different states to support the Hunter's Hope mission!

Hunter James Kelly Research Institute



University at Buffalo's Center of Excellence for Bioinformatics and Life Sciences houses the HJKRI in Buffalo, NY

When Co-Founders Jim and Jill Kelly began Hunter's Hope in 1997, one of their primary goals was funding research to find treatments and ultimately a cure for Krabbe and other Leukodystrophies. As time progressed it became clear that a central location exclusively devoted to Krabbe and similar diseases was the best way to advance research efforts.

Accordingly, in 2008, Hunter's Hope joined the University at Buffalo to create the Hunter James Kelly Research Institute (HJKRI). To maximize its effectiveness, the HJKRI approaches research from two primary perspectives — *Basic Science*, which involves laboratory based research exploring the

animal and cellular models of the disease, and *Clinical Research*, which studies the disease in affected patients. This comprehensive method facilitates new insight into Krabbe and other Leukodystrophies, paving the way to improved treatments and a cure in the most efficient manner possible.

Basic Science

The Basic Science Research at the HJKRI, led by Lawrence Wrabetz, MD, is comprised of six state-of-the-art laboratories devoted to studying the cause, effects, and potential therapies of Krabbe Disease and other myelin disorders. The researchers at the HJKRI create cellular and animal models to analyze the complex details of the disease, to progress research from the animal model to clinical trials, and ultimately, better treatments and a cure. In 2013, much progress was made in the development and work of these laboratories.



Lawrence Wrabetz, MD, Director of the HJKRI

Below are the main areas of focus, essential to discovering better treatments and ultimately a cure for Krabbe and other Leukodystrophies.

Pathology of Krabbe Disease

In 2013, the team at the HJKRI worked to determine the pathology of Krabbe, or how the disease is caused and its specific effect on the brain, peripheral nerves, and the body as a whole. Researchers used cellular and animal models to understand the effect of low GALC in each of the different cell types. Additionally, they studied its effect on myelin and the overall degeneration of the nervous system, and are working to identify other toxic substances (including the known toxin psychosine) that contribute to the damaging effects of the disease. This

important research will continue in the coming year.



Researchers at the HJKRI work diligently in their labs to further advance the research and study of Krabbe and other Leukodystrophies

Predicting Onset

Predicting disease onset, or when symptoms will occur in a patient, is crucial to ensuring all Krabbe patients receive treatment at the optimal time. This is especially important for children identified through newborn screening. Throughout the past year, HJKRI researchers explored how different mutations of the GALC gene cause more benign or more severe variations of Krabbe, and how the most common GALC mutation, the 30-kb deletion, causes a different pathology than other mutations of Krabbe.

This exciting area of research holds tremendous promise, as the HJKRI's Daesung Shin, PhD, and Laura Feltri, MD, have found that some mutant GALC proteins never arrive to the right part of the cell. In 2014, Dr. Shin is exploring whether GALC activity is more important in specific parts of the cell. If this is the case then the test for GALC activity should only be performed on these most significant parts. This could improve the reliability of predicting the onset of disease and if a mutation will actually cause disease.

Better Treatments and a Cure for Krabbe and other Leukodystrophies

Currently, the only successful treatment proven to halt the progression of Krabbe Disease is cord blood transplant. Unfortunately, it is available only to those diagnosed before the onset of symptoms, emphasizing how critical it is for each state to add Krabbe Disease to its newborn screening panel. In their efforts to find better ways to diagnose in time for effective treatment, researchers have come to believe that combining treatments may offer more promise.

In 2013, through the use of cellular and animal models, the HJKRI researchers investigated how to compensate for the known limitations of cord blood transplants and gene therapy by improving these methods and unearthing alternative treatments. They also explored the reason psychosine levels are elevated in Krabbe Disease and began working to determine if inhibition of psychosine decreases the severity of disease in the animal model. Additionally, the HJKRI researchers worked together with other important researchers of Krabbe Disease to find new combinations of treatments that will work faster and better than they do alone. This research will continue until the ultimate goal of a cure is realized.

Clinical Research

The Clinical Research Center, led by Thomas Langan, MD, works to improve understanding of the natural history of Krabbe Disease, what factors and tests best predict its onset and severity, and which treatment options are most effective.

In 2013, Hunter's Hope hired Erin Connors, M.Ed., as Coordinator of Clinical Care and Research. Ms. Connors works primarily at the Institute as a representative of the Hunter's Hope staff to enhance communication and progress made on behalf of affected families.

Thomas Langan, MD, Clinical Research Director at the HJKRI

World Wide Registry for Krabbe Disease

Since its inception, Hunter's Hope has been collecting invaluable medical information from affected families to gain better insight into Krabbe Disease. In 2008, this registry officially became the Krabbe World Wide Registry (WWR) and is now at the center of all clinical research at the HJKRI.

In 2013, with the hiring of the new Clinical Care and Research Coordinator, Erin Connors, a new surge of energy has been given to the WWR to ensure it reaches its maximum potential. The information catalogued in the WWR provides vital insight into diagnosis, outcomes, symptom management, and treatment. Throughout the past year, several research projects were carried out using the information contained in the WWR. This work will continue into the coming year.

Role of Psychosine in Krabbe Disease

In 2013, through a collaborative effort with the HJKRI, Joseph Orsini, PhD, from New York State's Newborn Screening Wadsworth Laboratory, and Dieter Matern, MD, PhD, from the Mayo Clinic are investigating the role of psychosine in Krabbe Disease to determine if its increased levels are associated with the onset of disease in patients identified through newborn screening. Preliminary results suggest that measuring psychosine in newborn dried blood spots could serve as a second tier test in NBS for early infantile Krabbe Disease, determine disease progression in late onset Krabbe, and ascertain potential for disease progression following transplant. This collaboration will proceed into 2014.

Mutation Analysis for Individuals with Positive Screens for Krabbe

Throughout the past year, the team of researchers at New York State's Newborn Screening Wadsworth Laboratory continued to work with the HJKRI to analyze genotypes of known Krabbe patients. Year after year, through newborn screening and the expansion of the Krabbe World Wide Registry, an increasing amount of patient genotype/phenotype correlations are helping physicians more accurately predict the onset and severity of each specific form of Krabbe. After conducting mutation analysis on saliva and newborn blood spots, results are compared with the clinical course of the disease to provide genotype/phenotype correlations. This work will carry on in the coming year as it greatly enhances diagnosis and treatment for all Krabbe patients.

Family & Medical Symposium



2013 Hunter's Hope Family & Medical Symposium Families

The 2013 Hunter's Hope Annual Family and Medical Symposium was held at Holiday Valley Resort in Ellicottville, New York, from July 22nd through the 28th. At the 2013 Symposium, we hosted 39 families affected by Krabbe or other Leukodystrophies, together with over 60 researchers and medical experts.

Medical Symposium

At the 2013 Medical Symposium, prominent newborn screening leaders from New York, New Jersey, Missouri, Illinois, and Michigan attended, providing an update on current or proposed Krabbe newborn screening programs in their states. This initiated the first step in expanding the New York Krabbe Newborn Screening

Krabbe Consortium to a Multi-State Consortium, ensuring that all states screening for Krabbe Disease at birth will be in communication, learning from each other and discussing improvements to follow up protocols and the standardization of patient care. Discussions also included treatments of animal Krabbe models such as gene therapy and Cord Blood Transplant, MRI findings and neuropathology of children transplanted for treatment of Krabbe Disease, newborn screening techniques, genotype/phenotype correlations, remyelination of the central nervous system and more.



Top: 2013 Hunter's Hope Medical Symposium Attendees
Bottom: Marcus (Krabbe Newborn Transplant)
meets some of the researchers and doctors at the
2013 Symposium

One of the most impactful components of the Medical Symposium is the opportunity to introduce researchers to families affected by Krabbe and newborn screening. This provides reallife examples of the difference their work makes for our families and the urgent need to continue to move forward, whether in basic science research, newborn screening, or clinical care.



Laura (MLD) prepares for the balloon release with her mother and sister

Family Symposium

In 2013, the Foundation welcomed 39 families affected by Krabbe or another Leukodystrophy for a week of learning, sharing, and fun. Families attended educational sessions led by the world's leading experts, to learn the most current information about the diseases plaguing their children, so parents can provide their children with the best possible care. In addition, families also had numerous opportunities

throughout the week to form relationships with one another, providing them with the hope and support needed as they cope with the effects of these devastating disorders. The magnitude of the love and hope felt throughout the week is difficult to put into words.



Jim Kelly gives Sal (MLD) a jersey

Hunter's Hope strives to make it possible for families to attend the Symposium, regardless of their financial capabilities. The

Foundation covered all meal and lodging expenses for the week.

For families unable to afford the cost of travel, the Foundation awarded over \$17,000 to families who would not otherwise be able to attend.



Left: John (Krabbe) receives a kiss from a horse their to give families carriage rides Middle (Left to Right): Katelynn (MLD), Lauren (Krabbe) and Reesa (Krabbe) arrive with their mommies Right: Jill Kelly holds Elias (Krabbe) in between sessions

Family Care Programs

Hunter's Hope is fully committed to providing encouragement, education and support to the over 700 families affected by Krabbe and other Leukodystrophies that have registered with the Foundation. To achieve our mission, our Family Care Programs encompass key areas designed to meet the needs of our families.

When an affected family registers with Hunter's Hope, our Family Programs Representative makes personal contact with the family to inform them of the programs available through Hunter's Hope and to make sure they know they are not alone. This relationship and personal contact is maintained throughout each year.

In 2013, over 500 cards and 39 care packages were sent to affected children and their families throughout the year – to celebrate a birthday, in remembrance of a child's heaven date, to welcome a new family to Hunter's Hope, or just to let someone know we were praying for them as they walked through a particularly challenging time.

The following programs have been established to support and encourage those afflicted, and their families, as they struggle to endure, adjust, and cope with the demands of these fatal illnesses:

Hope For Life

When a child is diagnosed with Krabbe or a similar disease, the prognosis is grim. Yet, everyday, the children affected by these dreadful diseases are defying the expectations that their doctors may have placed on them. *Hope for Life* shares stories of hope and helpful resources for parents as they care for and enjoy their child—because every breath is a gift.



Kenan (Krabbe) relaxes during pool therapy



Hunter Kelly, the day he was diagnosed with Krabbe

Wall of Fame

The Wall Of Fame is a section on the Hunter's Hope website to honor our heroes.

It also provides families a place to share links to their caring bridge sites, websites, and their family's location to encourage relationships and support within their communities. In the past year, we added 79 beautiful faces to the *Wall of Fame*, which honors nearly 340 affected children.

Equipment and Supply Exchange

Through this program, Hunter's Hope enables families to ship medical equipment and supplies they no longer need to other

families. The Foundation helps place the equipment with a family in need, and also covers the cost of shipment, which can be costly. In 2013, Hunter's Hope provided \$45,427 worth of medical equipment and supplies to children affected by Krabbe and other Leukodystrophies.

Hunter's Homes

In coordination with the Ronald McDonald House in Durham, NC, the Foundation provides our Hunter's Home to Leukodystrophy families whose child is being treated or evaluated at Duke University Medical Center. For children who undergo cord blood transplantation, the family needs to be near the hospital for six months to a year. Through the Hunter's Home, affected families are given a home away from home, enabling parents to focus on caring for their child. In the future, we hope to expand the Hunter's Homes as a resource to our families visiting Clinical Centers of Excellence.



The Ronald McDonald House in Durham, NC houses the Hunter's Home

Hunter's Wish Gift

Through *Hunter's Wish Gift*, we help provide for unique or extreme circumstances so that our families can provide the best possible care for their child. Our most requested Wish Gift is for assistance in purchasing a wheelchair accessible van so families are able to travel safely with their growing child. We are working hard to find new and innovative ways to meet this need for our families.



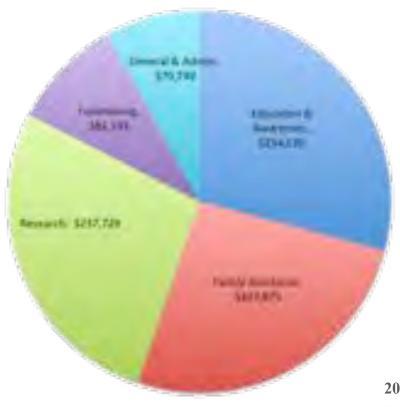
Kaden kissing his little sister Kylie

Kaden's Kisses

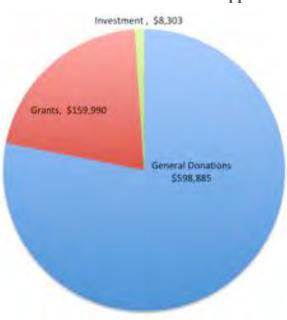
The *Kaden's Kisses* Fund is a special family program that was established in 2009 through Hunter's Hope by the Brunner family in honor of their son Kaden, after he died in a tragic automobile accident. The hope of this program is to share Kaden's love with families dealing with the loss of a child. In 2013, over \$30,000 was provided to families grieving the loss of a child, to help alleviate some of the burden associated with end of life expenses.

Financial Position

2013 Program and Support Expenses







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